

## DYSTHANASIA: NURSING PROFESSIONALS' PERCEPTION

Milene Barcellos de Menezes<sup>1</sup>

Lucilda Selli<sup>2†</sup>

Joseane de Souza Alves<sup>1</sup>

Menezes MB, Selli L, Alves JS. Dysthanasia: nursing professionals' perception. Rev Latino-am Enfermagem 2009 julho-agosto; 17(4):443-8.

*Dysthanasia means slow and painful death without quality of life. This study aimed to know whether nurses identify dysthanasia as part of the final process of the lives of terminal patients hospitalized at an adult ICU. This is an exploratory-qualitative study. Data were collected through semi-structured interviews with ten nurses with at least one year of experience in an ICU, and interpreted through content analysis. Results indicate that nurses understand and identify dysthanasia, do not agree with it and recognize elements of orthonasia as the adequate procedure for terminal patients. We conclude that nurses interpret dysthanasia as extending life with pain and suffering, while terminal patients are submitted to futile treatments that do not benefit them. They also identify dysthanasia using elements of orthonasia to explain it.*

**DESCRIPTORS:** terminally ill; euthanasia; nursing; bioethics

## DISTANASIA: PERCEPCIÓN DE LOS PROFESIONALES DE ENFERMERÍA

*Distanasia significa muerte lenta, con sufrimiento y sin calidad de vida. En esta investigación se buscó conocer si los enfermeros identifican la distanasia como parte del proceso final de la vida de personas en estado terminal, internadas en una UTI para adultos. El estudio es de naturaleza exploratoria, con abordaje cualitativo. Los datos fueron recolectados por medio de entrevista semiestructurada con 10 enfermeros con un mínimo de un año de experiencia en UTI; los datos fueron interpretados por el análisis de contenido. Se obtuvo como resultado que los enfermeros comprenden e identifican la distanasia y se oponen a la misma, presentando elementos de ortotanasia como procedimiento adecuado para pacientes en estado terminal. Se concluye que los enfermeros interpretan la distanasia como el prolongamiento de la vida con dolor y sufrimiento, en el cual los pacientes terminales son sometidos a tratamientos fútiles que no traen beneficios. También identifican la distanasia, usando elementos de la ortotanasia para hacerla explícita.*

**DESCRIPTORES:** enfermo terminal; eutanasia; enfermería; bioética

## DISTANÁSIA: PERCEPÇÃO DOS PROFISSIONAIS DA ENFERMAGEM

*Distanásia significa morte lenta, sofrida e sem qualidade de vida. Nesta pesquisa buscou-se conhecer se os enfermeiros identificam a distanásia como parte do processo final da vida de pessoas em terminalidade, internadas em UTI adulto. O estudo é de natureza exploratória, com abordagem qualitativa. Os dados foram coletados por meio de entrevista semiestructurada com 10 enfermeiros com, no mínimo, um ano de experiência em UTI, e interpretados pela análise de conteúdo. Teve-se como resultado que os enfermeiros compreendem e identificam a distanásia e se opõem à mesma, trazendo elementos da ortotanásia como procedimento adequado para pacientes em terminalidade. Conclui-se que os enfermeiros interpretam a distanásia como o prolongamento de vida com dor e sofrimento, onde os pacientes terminais são submetidos a tratamentos fúteis que não trazem benefícios. E também identificam a distanásia, usando elementos da ortotanásia para explicitá-la.*

**DESCRIPTORES:** doente terminal; eutanásia; enfermagem; bioética

<sup>1</sup>RN, e-mail: mimibm@pop.com.br, joseane.ars@gmail.com; <sup>2</sup>Adjunct Professor, Universidade do Vale do Rio dos Sinos, UNISINOS, Brazil, e-mail: lucilda@unisinobrasil.br

## INTRODUCTION

*D*ysthanasia is a little known term, but which is oftentimes practiced in the health area. It is a subject of interest in bioethics and according to the Bioethics Dictionary it is translated as "difficult or painful death, used to indicate the extension of the dying process through treatment that only prolongs patients' biological life. It has neither quality of life nor dignity. It can also be called Therapeutic Obstinacy"<sup>(2)</sup>.

It is a practice that aims to extend the life of terminal patients, but subjects them to much suffering. This practice does not extend life; it rather extends the dying process. The advancement of science and its implementation oftentimes compromises the quality of life of people who suffer, affecting their dignity. Palliative care and respect for patients' rights are efficient means to prevent dysthanasia.

We chose to deepen understanding of the theme of dysthanasia because it is a reality in nursing professionals' daily practice, which is little discussed despite being a situation that causes much suffering for patients whose lives are maintained without keeping quality of life in perspective.

This study provides an opportunity to think and encourages discussion not only in nursing but also with interdisciplinary groups since the problem affects patients attended by professionals from different knowledge areas. We sought to work with nursing professionals because they experience dysthanasia in ICUs and also because through them it is possible to identify new ways to attend terminal patients and to obtain knowledge about the theme. Hence, this study aimed to know whether nurses understand and identify situations of dysthanasia in intensive care units.

We believe this study can foster discussion about the theme among peers and lead people to re-think the dilemma between dysthanasia and orthonasia, that is, between extending life at any cost, which causes suffering, or accepting death at the right moment as part of life. Yet, under this perspective, when nurses and other health professionals are able to identify situations of dysthanasia and orthonasia they are better prepared to make decisions regarding the most appropriate treatment and how to manage family members.

## METHOD

This is an exploratory-qualitative study<sup>(3)</sup>. Researchers who employ qualitative strategies utilize

experiences, events of daily life and also structures and institutions as raw material, though they see these as objective human actions. Qualitative research has particular questions. It attends a gap that cannot or could not be quantified<sup>(3)</sup>. It works with the universe of meanings, reasons, aspirations, beliefs, values and attitudes<sup>(3)</sup>.

Exploratory research is more than simply observing and describing a given phenomenon; it investigates its complex nature and other factors to which the phenomenon is related<sup>(4)</sup>.

The research was carried out in an adult intensive care unit of a hospital in Porto Alegre, RS, Brazil. The sample was composed of ten nurses working in an adult ICU and experiencing dysthanasia in their daily practice, both genders, from three shifts: morning, afternoon and night. Only those with at least one year of experience in ICUs were considered to compose the sample.

These professionals were chosen because they experience dysthanasia in ICUs and also because they can help to identify new ways to attend terminal patients and provide better knowledge of the theme.

Data were collected through semi-structured interviews on the following themes: terminality, futile treatment, understanding of dysthanasia, and aid to the terminal patient. Semi-structured interviews associate open and closed questions and the researcher can talk about the theme under study without having to stick to pre-formulated questions<sup>(3)</sup>.

Interviews were recorded with an audio tape recorder and fully transcribed afterwards. They were scheduled and conducted in a room available at the time to ensure interviewees' privacy. The interviews were about 30 minutes in duration in March 2008 in three different shifts: morning, afternoon and night.

Data were analyzed through content analysis, which aims to understand collected data, broaden knowledge in regard to the studied subject, confirm or disaffirm the study assumptions and obtain answers to initial questioning<sup>(3)</sup>. Central meanings were underlined and extracted from the data and, after comparison, were grouped by similarities and differences into categories<sup>(3)</sup>.

Categories were composed after densification and data saturation. Afterwards, we sought to understand collected data through the theoretical framework, elaborating links between data and theoretical references<sup>(3)</sup>.

The study was submitted to the hospital's Research Ethics Committee for its evaluation and approval according to Protocol No. 019/08. Approval was obtained on February 27, 2008 according to Resolution 196/96 from the National Health Council.

A free and informed consent agreement was provided to participants where in the study subject, objectives and justifications were clarified. The free and informed consent agreement was signed with two copies, one for the participant and the other for the researcher.

## DATA RESULTS AND DISCUSSION

With data densification, four analysis categories emerged. These are identified by the following: a) identification and understanding of dysthanasia; b) dysthanasia or orthonasia; c) futile treatment: the family facilitates dysthanasia d) nurses' participation.

First category: identification and understanding of dysthanasia

This category aims to present and analyze collected data related to the identification and understanding of dysthanasia reported by the participants and based on their answers.

"The term dysthanasia is defined as slow, anguishing death with much suffering"<sup>(5)</sup>.

*[...] dysthanasia means dying with pain, right? Means dying with suffering (S1).*

The exaggerated extension of death, where patients are subject to a process of intense pain and suffering, is a process that extends agony, with no possibility of healing or improvement. It extends agony with no expectation of success or a better quality of life; it does not aim to prolong life but rather to prolong the process of dying.

*I believe that we do a lot of dysthanasia, many times we extend patients' suffering (S2).*

Another participant mentions the extension of suffering not of life.

*[...] when you extend a person's life without any therapeutic perspective, it isn't worth it, it will only extend suffering (S5).*

Another understanding of dysthanasia is related to distancing one from death.

*[...] you distance the patient from death, use measures to distance patients from death (S3).*

Dysthanasia does not benefit patients.

*[...] you invest something else in patients, only that you're going to do things that will not favor them (S3).*

This participant refers to a cruel death.

*[...] dysthanasia is dying in a cruel manner (S4).*

The reports of some nurses indicate they understand and identify dysthanasia in the unit. They frequently identify it when everything possible was already done or every possible treatment was performed and was not effective. There is an understanding that it represents a cruel death, with pain and much suffering, not providing any benefit, and distances death and life.

When one implements therapeutic obstination to terminal patients who do not have any chance of cure or of changing their health condition, it simply results in extending the dying process, causing more pain and suffering to patients who are at the end of their lives<sup>(6)</sup>.

Many patients are submitted to a painful, anguishing, unnecessary and expensive dying process<sup>(7)</sup>.

Interviews indicate that expensive medication and exams are used on patients with no perspective on quality of life.

*[...] there's no perspective of life, so an expensive therapeutic is usually used (S8).*

The reports show that technology has been inappropriately used and the exaggerated extension of life is committed on a large scale, especially in the treatment of terminal patients<sup>(6)</sup>.

Terminal patients are submitted to treatments, invasive procedures and techniques in ICUs, in which suffering is greater than benefits gained because cure is no longer possible.

Second category: from dysthanasia and orthonasia

Terminal patients are those who are in the final phase of a disease with no chance of reverting their condition, even partially or temporarily, with the use of any known and implemented therapeutic measure<sup>(8)</sup>.

*Terminal patients are those patients in severe health conditions who don't have any prospects for quality of life after leaving the ICU (S7).*

As the disease develops, terminal patients reach a moment when it is no longer possible for them to recover and death is inevitable. Therapeutic measures at this stage do not increase survival; they only extend the dying process.

*[...] no patient is terminal in my point of view, there're patients with therapeutic limits, the term terminal patient seems... terminal seems there's nothing else you can do for people, but even at the hour of death there's a lot you can do for people (S6).*

Orthonasia means death at the right time, neither disproportionately abbreviating nor extending the dying process<sup>(9)</sup>.

Palliative care controls pain and improves quality of life. It does not aim to cure a disease or extend life as long as possible rather it aims to permit patients to live peacefully and comfortably.

Palliative care aims to alleviate suffering, unbearable pain and body degradation but does not completely eliminate them. Palliative care programs do not propose euthanasia, but there is a concern with patients' quality of life and well-being. There is no resuscitation equipment nor do they propose heroic treatments at ICUs<sup>(10)</sup>.

The concept of care is focused on care and not on a client's definitive care. Palliative care is associated with the work of a multidisciplinary team, to control pain and alleviate symptoms<sup>(11)</sup>.

Interviewees' reports show the maintenance of comfort as a priority and refer to elements of orthonasia, which means dying at the right time, as opposed to dysthanasia. Terminal patients are maintained with palliative care, controlling pain and symptoms, with a view to improve their quality of life.

*[...] we have to invest in patient's comfort, you know? Alleviate suffering, you know? Provide patients with a good analgesia, because there's nothing else to do besides treatment, so, I guess that comfort has to be a priority (S9).*

Many patients in ICU end up requiring palliative care. ICU nurses offer strong support and management of pain, alleviating terminal patients' suffering and pain.

*A terminal patient has a very poor prognosis, you know? A patient for whom all possible measures were implemented, the whole treatment and this patient has no... there's nothing more that can be done for him, everything possible was done and now what remains is to maintain the patient comfortably and wait for death to come (S1).*

Orthonasia is a more positive dimension of the right to die and consists of dying humanely, peacefully, an ideal death. It is the process of the humanization of death and alleviation of pain, but it does not abusively prolong death with the implementation of futile treatment, which would cause more suffering to terminal patients.

Orthonasia is the practice of not avoiding patients' death, rather it ceases investments that extend life at a medium term<sup>(12)</sup>.

Orthonasia is not applied to cases limited to intense suffering of any nature, whether it is pain or discomfort. It means suspending measures only related to the concept of therapeutic obstination, focusing on the maintenance of well being and taking necessary measures to meet this goal<sup>(13)</sup>.

As treatments can no longer restore health, attempts at healing become futile; one has to keep in mind that care is part of the treatment, not to incur dysthanasia<sup>(9)</sup>.

When the treatment no longer meets its objectives, when there are no real possibilities of success or improved quality of life, treatment becomes futile. Hence, one needs to stop useless measures and transfer efforts to alleviate pain, suffering, discomfort of dying, providing natural death, etc.. Death has no cure. It is noble to assume it is part of life.

Third category: futile treatment – the family facilitates dysthanasia

Futile treatment is when one does not meet the objective of postponing death, extending life, improving, maintaining or recovering quality of life, favoring the patient as a whole, improving the prognosis, comfort, well being, ending dependency on intensive medical care, preventing or curing disease, alleviating suffering and symptoms, restoring functions<sup>(14)</sup>.

Medical futility is understood as actions that do not maintain or restore quality of life, bring someone to consciousness, alleviate suffering or otherwise benefit patients; on the contrary, such actions causes intense suffering<sup>(10)</sup>.

*[...] the physician makes it clear, but the family doesn't want it, they prefer to make everything and we feel that the patient keeps suffering really, but then it's what you're saying about dysthanasia (S4).*

As medical therapy does not meet its objectives, which are to preserve health and alleviate suffering, it becomes futile or a burden. Then the obligation emerges to cease useless measures and intensify efforts to assuage the discomfort of dying<sup>(15)</sup>.

Following, the study shows that family members do not accept the condition of patients hospitalized at ICUs and prefer to implement any possible treatment.

*[...] the family does not accept we take out everything, that we just support the patient, that this patient is really terminal, you have to make it clear, but the family does not accept it, it's a family's decision (S10).*

Futile procedures with little chance of success should be abolished<sup>(16)</sup>.

Extending life, the quality of life, is a complex concept that science and technology transpose to the humanitarian dimension<sup>(13)</sup>.

Futile treatment does not benefit terminal patients; on the contrary, it postpones death and causes more agony, giving unfounded hope to family members. Futile treatment could be replaced by palliative care, however, family members do not accept the conditions of severely ill patients and manifest their desire to keep the treatment.

#### Fourth category: nurses' participation

The participation of nurses in the decision-making process is yet modest, that is, there are situations when they comply with prescribed treatment, which most of the time they do not agree with, while they could instead contribute more effectively by defending the autonomy of patients and their families.

The importance of interdisciplinary dialog is emphasized and this bioethical issue demands the involvement of health professionals and all those who, with competence and responsibility, are willing to reflect in ethical terms on the best practice to be implemented<sup>(17)</sup>.

*[...] I really think that nursing is not very concerned with this, also because the nursing work process doesn't permit us to discuss this issue, death.*

This report reveals that nurses neither contest the medical prescription nor do other physicians and people respect the adopted procedure.

*[...] nobody contests a medical prescription, you know, even among them...they respect each other a lot and if you think the proposed action is the one, go ahead.*

Decisions interrupting futile treatment include more attention to improve the nurse-physician-patient-family relationship in situations in which a cure is no longer possible. This becomes a procedure involving both nurses and physicians<sup>(14)</sup>.

*[...] we can contribute in respecting the patient as someone, you know, who is under minimum conditions of survival... but during shifts we can talk to physicians, put forwarded some of our views, some of them are really receptive, they even talk with us as we're talking now.*

Nurses report that they cannot influence decisions and that nurses should participate more so as to prepare the team.

*[...] we don't manage to influence decisions, don't manage to participate in this decision, I guess that nursing should also participate in this decision so as to prepare its team.*

In practice, the physician has to make this decision unilaterally and in isolation and does not share views due to lack of communication among professionals. There is also the perception that the decision to interrupt a given treatment, considered futile, is not always unanimous among professionals and supported by different physicians in the same institution. It is not uncommon to see a physician on duty to resume a previous treatment, motivated by his or her convictions, creating a vicious cycle, difficult to resolve, and which reflects the lack of dialog between the medical team itself<sup>(5)</sup>.

Finally, nursing has small participation in the decision of practices to be adopted, though it is possible, in some cases, for nurses to talk with physicians and put forward their views regarding procedures. A lack of interdisciplinary work among teams is evident. Decisions rest on a single person.

## FINAL CONSIDERATIONS

According to interviewees, nurses identify dysthanasia in their daily practice as a death suffered with much pain and the implementation of aggressive treatments, which only extend the process of dying. It extends suffering and not life, does not bring any therapeutic benefit and causes high costs to institutions.

Nurses identify dysthanasia but fight against it and instead provide orthonasia, always giving priority to comfort and pain relief in a calm and pleasant environment aiming at quality of life, the most positive dimension of the right to die, not abusively extending the process through high-end technology, but rather, interaction between teams. Decision-making little involves nurses but mostly is restricted to physicians.

Data collected shows that nurses understand dysthanasia as extending life with pain and suffering and work their best to assure patients' dignity in their living and their dying, controlling symptoms of organic disorder and providing comfort and well-being to terminal patients.

We conclude that nurses understand dysthanasia in the unit and that terminal patients are submitted to futile treatments that extend death and do not benefit

them. Nurses also identify dysthanasia but put forward elements of orthonasia to place a priority on providing comfort, that is, dying at the right time.

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